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Aligning Concerns in Telecare: Three Concepts to Guide the Design of Patient-Centred E-Health

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Abstract. The design of patient-centred e-health services embodies an inherent tension between the concerns of clinicians and those of patients. Clinicians' concerns are related to professional issues to do with diagnosing and curing disease in accordance with accepted medical standards. In contrast, patients' concerns typically relate to personal experience and quality of life issues. It is about their identity, their hopes, their fears and their need to maintain a meaningful life. This divergence of concerns presents a fundamental challenge for designers of patient-centred e-health services. We explore this challenge in the context of chronic illness and telecare. Based on insights from medical phenomenology as well as our own experience with designing an e-health service for patients with chronic heart disease, we emphasise the importance – and difficulty – of aligning the concerns of patients and clinicians. To deal with this, we propose a set of concepts for analysing concerns related to the design of e-health services: A concern is (1) *meaningful* if it is relevant and makes sense to both patients and clinicians, (2) *actionable* if clinicians or patients – at least in principle – are able to take appropriate action to deal with it, and (3) *feasible* if it is easy and convenient to do so within the organisational and social context. We conclude with a call for a more participatory and iterative approach to the design of patient-centred e-health services.

Keywords: Patient-centred e-health, Patient-clinician interaction, Patient-provider relationship, Medical phenomenology, Participatory design, Alignment of concerns

1. Introduction

Healthcare costs are escalating in all OECD countries due to, on the one hand, advances in medical science, technology, treatments and therapies, and on the other hand, a dramatic increase in patients with chronic diseases, such as diabetes and heart disease, associated with modern lifestyles and aging populations. At the same time, patients demand higher quality and more personalised care, putting extra pressure on governments and healthcare providers to increase access to quality care while maintaining or decreasing costs. It is often argued that one way of achieving this

may be through an increased emphasis on ‘self-care’ and ‘patient empowerment’ supported by new patient-centred e-health services, such as personal health records (PHR), telehomecare, and remote monitoring (European Commission 2012; All Party Parliamentary Group on Global Health 2014).

There are great expectations for the potential of this approach to transform care, increase access, promote quality and lower costs (Holman and Lorig 2004; Street Jr et al. 2005; Koch 2006; Johnston et al. 2013). However, at present, these benefits remain largely hypothetical. Clinical efficacy and cost-effectiveness have not been documented (Dedding et al. 2011; Archer et al. 2011), and several authors warn that patient-centred e-health services may have potentially adverse effects on the patient-provider relationship, and that patients may be forced to take on tasks and responsibilities that they do not feel capable of coping with (Neuhauser and Kreps 2003; Dedding et al. 2011; Oudshoorn 2011; Chen et al. 2013).

The use of IT to improve healthcare delivery is nothing new, of course. Just think of electronic medical records (EMR), computerised physician order entry (CPOE), picture archiving and communication systems (PACS), and laboratory information systems (LIS). Patient-centred e-health services, however, are a significantly different breed of health IT applications, because they presume patients will be active users. It is therefore essential to take the perspective of the patient seriously and understand that patients have fundamentally different concerns and needs than physicians, nurses and other traditional users of e-health applications (Baron 1985; Toombs 1992; Carel 2011). These concerns and needs must be carefully addressed if patient-centred e-health services are to be successful. However, it seems that researchers and designers, in general, do not truly understand the scope and complexity of this task. Indeed, as Storni (2014) has recently pointed out, ‘the majority of self-monitoring technology and PHR (Personal Health Records) platforms are designed from the perspective of medical experts rather than patients’ (p. 407).

The objective of this article¹ is to help remedy this situation by, first, examining the difference between the way clinicians think about disease and the way patients experience their own illness, and, second, exploring the implications this has for the design of patient-centred e-health services. In doing so, we draw on insights from medical phenomenology (Baron 1985; Toombs 1992; Carel 2011) as well as on empirical insights from our own process of designing an e-health application for clinicians and patients with chronic heart disease. We argue that the dominant medical view of disease as a biological phenomenon or bodily dysfunction is at odds with patients’ subjective experience of serious chronic illness as a life crisis (Carel 2011), and that aligning the concerns of patients and clinicians is a prerequisite

¹ This article extends the empirical material and offers an extensive discussion of the theoretical argument originally developed in our conference paper ‘Alignment of Concerns: A Design Rationale for Patient Participation in eHealth’ (Andersen et al. 2014). The paper also extends the methodological argument presented in a book chapter ‘From Prototype to Product: Making Participatory Design of mHealth Commercially Viable’, which is part of the edited book ‘Participatory Design & Health Information Technology’ (Andersen et al. 2017)

for the successful design and implementation of patient-centred e-health services. This does not imply that patients and clinicians need to have, or develop, identical perspectives on illness and treatment, but rather that their respective concerns and needs must be recognised, respected and reconciled. Otherwise, there is a high risk that either patients or clinicians will be reluctant or unwilling to adopt the service.

Our study offers three contributions to the literature on patient-centred e-health services. First, existing research rarely pays much attention to how patients' perspectives, concerns and needs differ from those of clinicians and other health professionals. In response, we examine the experience of illness as an embodied phenomenon and highlight how it differs from the biomedical perspective of the physician. Second, we provide a detailed analysis of the design of an e-health service to support the treatment of heart patients with an implantable cardioverter-defibrillator (ICD). In doing so, we show that patients and clinicians have divergent perspectives and concerns that may prove difficult to align. Third, we develop conceptual guidelines for understanding and designing patient-centred e-health services that explicate three dimensions of alignment between patients' and clinicians' concern.

2. Patient-centred e-health services

Early research and development of healthcare IT focused on administrative information systems such as hospital information systems (HIS) and laboratory information systems (LIS) intended to serve a single hospital or laboratory. Users consisted mainly of administrators, physicians and other health professionals (Bath 2008; Haux 2010). With the emergence of health informatics in the 1990s, the scope broadened to include systems spanning multiple hospitals, telehealth, global information infrastructures, and strategic information management (Shepherd 2007; Fitzpatrick and Ellingsen 2013). The users were still primarily hospital staff and administrators (Cho et al. 2009; Hara and Hew 2013).

However, over the last decade, patients have come to play an increasingly important role in their own treatment and care, and under the umbrella of e-health researchers and designers have begun to extend the network of users to include patients (and their relatives) (Ahern et al. 2008). Examples of e-health services that target patients include patient-provider portals (e-visit and e-booking), telehomecare platforms (Koch 2006) and PHRs (Lafky and Horan 2008; Piras and Zanutto 2014). Furthermore, there is currently a rapid growth in consumer-oriented health websites, mobile applications, and social software that enable patients to engage in self-management and exchange experience and advice to better cope with day-to-day personal health issues (Hartzler and Pratt 2011; Morgan and Trauth 2013). It is still too early to tell where this new technological trend will lead, but it is likely to have important impacts on the future of healthcare (Baird et al. 2011; Dedding et al. 2011; Oudshoorn 2011).

It is generally expected that patient-centred e-health services will facilitate patient participation, self-management, and empowerment (Dedding et al. 2011; Archer

et al. 2011; European Commission 2012; All Party Parliamentary Group on Global Health 2014). Such services can, for instance, become a 'supplement to existing relationships and forms of care' (Dedding et al. 2011), improving behavioural outcomes through tailored communication and increased interactivity (Neuhauser and Kreps 2003). It is also suggested that e-health has the potential for creating 'favourable circumstances for improvements or strengthening of patient participation' (Dedding et al. 2011) and for ensuring 'more transparency and empowerment' (European Commission 2012, p. 14). For example, PHRs and various health sites may make patients better informed and empowered (Lafky and Horan 2008; Piras and Zanutto 2014) and thereby possibly better equipped for 'self-management' (Holman and Lorig 2004) and 'shared decision-making' (Neuhauser and Kreps 2003). E-health can also function as a lever for engaging health professionals in working together with patients (Tang and Lansky 2005), thus, promoting greater self-management and individual responsibility on the part of the patient (All Party Parliamentary Group on Global Health 2014; Waycott et al. 2014).

More recent studies examine how self-tracking and patient-generated data may support collaboration between patients and providers. Patel et al. (2012) describe how regular symptom tracking by patients who use a personal health information management tool in cancer care can support communication between patients and clinicians. Hartzler et al. (2016) show that patient-reported outcomes (PROs), trackers and dashboards can be a promising approach for integrating patient-generated data into prostate cancer care.

However, early experiences with patient-centred e-health services also point to many challenges and unintended consequences that should be taken into consideration when designing future applications and services. In CSCW, Bardram et al. (2005) described, more than a decade ago, the emergence of a new division of work in telecare. They studied home-based monitoring and treatment of hypertension using a self-inflatable blood pressure monitor and a PDA and found that unanticipated practices emerged. With remote monitoring, patients must learn to adhere to the frequency of the measurements and assume responsibility for using the medical equipment correctly. Dedding et al. (2011) warn that these services may 'disturb' patient-clinician relations and lead to more 'sick work' for the patients. Therefore, they advise, 'more attention should be paid to the redistribution of tasks and responsibility to patients.' Similarly, Piras and Zanutto (2014) describe how a PHR for paediatric diabetes management generated 'tensions' between patients, relatives and physicians because it was perceived as 'an intrusion into the personal sphere' of the family.

There can also be discrepancies between what patients want to share and what clinicians find useful. Jacobs et al. (2015) identify such misalignment when comparing what patients want to share in breast cancer treatment with what healthcare providers prefer. Miscommunication can happen when patients are given the opportunity to track health related data. Physicians may not find the data relevant, they may have different goals than patients, or they may simply lack the time for reviewing it. This

leads to unmet expectations and makes patients dissatisfied and disappointed to an extent that it creates conflicts between the patient and clinician (Chung et al. 2016).

Another unintended consequence may therefore be added responsibilities and extra costs for providers (Dedding et al. 2011) – costs that are often not covered by existing reimbursement models. A related, but not as easily quantified consequence could be that patients develop new expectations; expectations that clinicians cannot meet (Nielsen 2015). Clinicians may also feel that their professional practice is challenged or even undermined by the new technologies. For example, Chen et al. (2013) highlight the challenges of e-visits, where patients and physicians communicate online, and question whether physicians can build trust and engage in diagnosis without being able to interview, observe, and examine the patient in person. Similarly, Oudshoorn (2011) describes how health professionals working with telecare need to learn new skills such as how to create a kind of intimacy at a distance. She also describes how telecare can have the unintended consequence of shifting responsibility onto patients so that self-care is forced upon them whether they like it or not. In a similar vein, Langstrup (2013, p. 7) describes how ‘family members become, willingly or unwillingly, parts of the chronic care infrastructure.’

In sum, delivering on the promise of patient-centred e-health is easier said than done. It requires an in-depth understanding of not only the technology but also the needs and concerns of all the relevant actors, in particular clinicians and patients. Paraphrasing Fitzpatrick and Ellingsen (2013), there is an urgent task for CSCW, and related fields engaged in patient-centred telecare research, of conceptualising and understanding how absent-yet-present patients and clinicians can collaborate.

3. Medical phenomenology: Divergent meanings of illness and disease

We suggest that an understanding of the difference between the perspectives and goals of patients and clinicians, as well as the variation in needs and concerns within these two groups of actors, is key to successful design of e-health services. As S. Kay Toombs (1992) has pointed out in her seminal book on the meaning of illness, there is a ‘decisive gap’ between the way illness is experienced by the patient and the way in which physicians conceptualise disease in biomedical terms such as symptoms, diagnoses, pathology, treatment, and prognosis. ‘Consequently, rather than representing a shared ‘reality’ between them, illness represents in effect two quite distinct ‘realities’” (ibid., p. 10). Generally speaking, patients may be said to experience illness as a unique, personal event that transforms their bodily awareness and disrupts their everyday lives, including their roles and relationships with others (Charon 1992; Pickard and Rogers 2012). In contrast, physicians may be said to understand disease as an entity in itself, a biological phenomenon that can be categorised and diagnosed as a known illness, for instance as a particular case of ‘diabetes’ or ‘ischemic heart disease,’ and treated according to scientifically tested procedures (Baron 1985; Toombs 1992; Montgomery 2005).

3.1. Different objects and projects

Consequently, physicians and patients focus on different aspects of illness. According to phenomenologists such as Toombs (1992) and others (Baron 1985; Carel 2011), patients encounter their illness as an immediate lived experience, which manifests itself as pain or other physical (or mental) problems that disrupt their normal functioning and demand their attention. The categories patients use to make sense of their illness are ‘primarily concerned with everyday life and functioning’ (Toombs 1992). Serious illness, and in particular serious chronic illness, does not just affect the body. It can affect one’s whole life, one’s relationships with others, and how one sees oneself (Öhman et al. 2003). Patients suffer because their illness constrains their agency and because it creates anxiety and fear, but they also suffer because ‘they feel isolated from others, because they feel alone’ (Biro 2012). In contrast, physicians are trained to ‘see’ the patient’s illness within a prescribed conceptual framework (the biomedical model of medicine), as a typical example of a disease. They conceptualise the illness in terms of abstract scientific constructs and in doing so primarily focus on ‘objective facts’ such as physical signs, clinical findings, and laboratory data (Toombs 1992; Montgomery 2005).

Another aspect of the gap between physicians and patients is that they are engaged in different ‘projects’ and, as a consequence, have different criteria of relevance. The goal of physicians is to diagnose the patient’s condition – to fit the particular case within disease taxonomies – and provide reliable and effective treatment in accordance with accepted practice standards, clinical guidelines, protocols, and so forth (Montgomery 2005). On the surface, this goal seems to match the patient’s needs. However, as Toombs (1992) has stressed, ‘the patient’s goals relate to the qualitative immediacy of his or her illness. They represent an attempt to integrate the experience into daily life.’ (p. 18). The overriding goal of patients is to come to terms with their changed situation and develop effective coping strategies that allow them to curb their anxiety and re-establish a meaningful life (Charon 1992; Öhman et al. 2003; Pickard and Rogers 2012). One consequence of these differences in priorities is that patients and physicians often disagree on what is relevant and what is not: ‘Since the ‘problem at hand’ is defined differently by patient and physician, according to goals that relate to their separate worlds, they do not share a system of relevance with respect to these goals.’ (Toombs 1992, p. 18).

3.2. Concerns change over time and vary between individuals

Although e-health design and research can surely benefit from paying attention to the ‘decisive gap’ between the lived experience of illness and the scientific, biomedical account of disease, this dichotomous portrait of patients’ and physicians’ perspectives nevertheless calls for nuances.

Firstly, we wish to underscore that neither patients’ nor clinicians’ concerns are static. An illness trajectory can, for the individual patient, involve great variation, e.g., in how the illness manifests itself, how one copes with it, reacts to treatment

options, and life circumstances – all factors that may cause patient concerns to change over time. Similarly, clinicians' concerns may change according to the observed developments in the patients' disease, coping strategies and life circumstances, as well as in the light of new knowledge, guidelines and treatment options.

Secondly, it should be noted that concerns vary amongst patients as well as physicians. Physicians' perceptions of the same disease are not necessarily identical or entirely based on a biomedical model of medicine. Pronounced professional specialisation often directs physicians' attention to particular biomedical indicators, and may lead them to interpret their role as carers differently. Even though medical work is a scientific practice founded on the application of evidence-based clinical guidelines (Sackett et al. 1996; Timmermans and Kolker 2004), it is also situated and interpretative because it involves '(...) the ability to work out how general rules – scientific principles, clinical guidelines – apply to the particular patient' (Montgomery 2005, p. 5). Furthermore, it is increasingly recognised that physicians, when applying clinical guidelines, to some extent include the patient's lived experience (Tang and Lansky 2005; Shepherd 2007).

Further, patients' experiences of and strategies for coping with a specific illness vary greatly. Differences in background, current life situation, and physical and mental condition may, for instance, cause some variance with regard to patients' ability and motivation to use health information and partake in own care (Tang and Lansky 2005; Lafky and Horan 2008; Baird et al. 2011; Hartzler and Pratt 2011). In the context of e-health it is particularly relevant to note that technologies such as health information sites and self-tracking devices are often framed as means to bridge the gap between patients and clinicians, because they enable patients to acquire knowledge about their own condition and treatment. This may also enable patients to tap into the medical paradigm and terminology (Finch et al. 2008; Felt et al. 2009). Chronically ill patients have been shown to be particularly prone to become so-called 'expert patients' who through the new technologies can engage with their clinicians as lay experts and partners, thus, making the relationship between patients and clinicians less characterised by hierarchy and different perspectives (Unruh and Pratt 2007; Piras and Zanutto 2014).

However, far from all patients can be described as 'expert patients'. Moreover, 'partnerships' between expert patients and their clinicians still involve a 'gap'. As Hunter (1991) has emphasised, while the use of common terms suggests that physician and patient are talking about the same things, 'often only the physical signs and their diagnostic labels are the same; the understanding and the concerns are entirely different' (p. 14). In fact, the difference in perspectives is typically so deep-seated that it results in a 'systematic distortion' of meaning in the patient-physician encounter (Toombs 1992). This is because of 'a fundamental distinction between the lived experience of illness and its conceptualisation as a disease state' (p. 31) and thus goes far beyond differing levels of knowledge about illness and disease (with the physician being regarded as the most knowledgeable). With reference to Pols (2012, 2013), we can say that patients' expertise and knowledge is of a very different

character than that of clinicians: It is about knowing how and when to act on ones own bodily experiences in order to cope with illness in everyday life (see also Hartzler and Pratt 2011; Storni 2015).

In conclusion, while it is important to recognise and understand these nuances, they do not change the overall point, convincingly argued by medical phenomenologists (Charon 1992; Toombs 1992; Carel 2011), that physicians and patients focus on different aspects of illness and that they often have starkly divergent concerns and priorities regarding treatment and ‘disease management’. On the contrary, the nuances mentioned above emphasise the challenges in designing patient-centred e-health services. Through our empirical cases, we show and discuss these challenges.

4. Research setting and method

The main findings presented in this paper derive from a large interdisciplinary research project, ‘Co-Constructing IT and Healthcare’ (2008–2012), carried out in a partnership between multiple hospitals and universities in the greater Copenhagen area in Denmark. The aim of the project was to understand the treatment and care for chronic heart patients with an implantable cardioverter defibrillator (ICD) and develop exploratory prototypes of a patient-centred e-health application to improve collaboration between patients and clinicians. An ICD is best understood as an advanced pacemaker, designed and configured individually to ensure a steady heart rhythm and, if needed, to deliver an electric shock to stop a fast and dangerous heart rhythm.

In a follow-up project, the SCAUT project (2014–2018), we continued research and development under more commercial conditions (see Andersen et al. 2017). Two additional industry partners joined the consortium; Medtronic, the world’s largest medical device company, and Rehfeld Medical, a Danish healthcare IT start-up. This paper is mainly based on the CITH project, however, we use the empirical data from the follow-up project to illustrate how the conceptual guidelines that we propose, helped us increase alignment of concerns among patients and clinicians.

The care for ICD patients involves multiple actors. We investigated the two main settings where the care takes place: the hospital’s heart centre and the patients’ homes. Nearly all patients are monitored remotely. Data is sent from patients’ home monitor to the heart centre for follow-up every three months or whenever an ‘event’ that clinicians need to address occurs. An event could be that the device registers atrial fibrillation [irregular heart beat] and notifies the heart centre. For each remote follow-up, a lab technician interprets the data and, if needed, the technician asks for a second opinion from a cardiologist or, in some cases, hands the case over to the cardiologist. Often they consult the patient’s electronic medical record and a special device record. When needed, they make a phone call to the patient to get more specific information for evaluating the condition. If there are any problems, the patient is either

referred to the local hospital for adjustment of his or her medication or the patient is called in to have the ICD adjusted at the heart centre. In most cases, however, no clinical action is needed.

4.1. Research methodology

Our overall research approach is based on Participatory Design (Simonsen and Robertson 2013). Participatory Design seeks to engage users and designers in a mutual learning process to understand current challenges and design new forms of IT support and new ways of organising the work (Kensing and Greenbaum 2013). Participatory Design has a strong methodological tradition for combining research and design inquiries in healthcare (Clemensen et al. 2007; Kanstrup et al. 2017) and there is a close connection between Participatory Design and CSCW studies (Kensing and Blomberg 1998).

More specifically, Participatory Design entails that prospective users engage in close collaboration with designers to develop a thorough understanding of the current practices and in defining the aim and specific design of a new information system, in this case a patient-centred e-health service.

4.2. myRecord: The patient-centred e-health prototype

As part of the CITH project, we designed and developed an e-health service called myRecord. It is an add-on to the existing remote monitoring system (Andersen et al. 2011), designed to empower patients who are capable and willing to engage with clinicians around the remote monitoring of their ICD (see Figure 1).

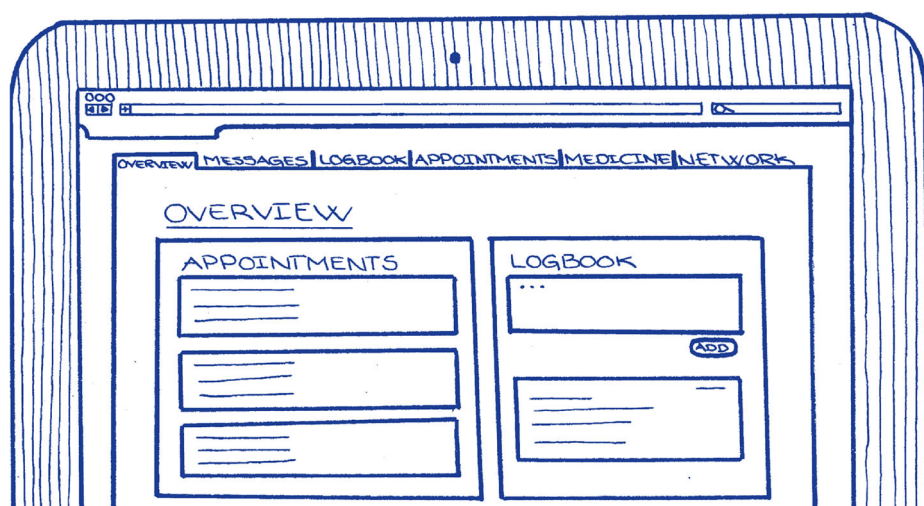


Figure 1. The features in myRecord: Overview, Messages, Logbook, Appointments, Medication list, and Patient network

myRecord offered several features, but the empirical material presented in this paper, centres on the features that support patients in preparing for each remote follow-up and in-clinic consultation. As part of the *preparation*, patients were prompted to complete a series of questions prior to the consultation. This meant updating and confirming their medication list and using their own vocabulary to raise questions about experienced problems or concerns. Further, patients were asked to report on their health status by ticking off symptom categories based on the New York Heart Association's classification scheme, e.g. shortness of breath or palpitation, and by specifying in which situations the symptoms occurred. Other features included a *logbook*, in which patients could keep a diary of symptoms and the development of their illness, and a *network* feature that allowed patients to share their information and get in touch with each other. For clinicians, myRecord offered a clinical summary, access to patients' preparations and logbook, and a feature for responding to patients, by either writing or dictating a message. A more extensive description of the different features and effects of myRecord have been published elsewhere (see e.g. Andersen et al. [2011](#)).

4.3. Data collection

In the early phases, we began by exploring existing practices in patients' homes and in the clinics. Then we launched the myRecord prototype to experiment with the IT support for the work of clinicians and patients. Based on these experiments, we adjusted the prototype, the tasks, and the roles, but we also learned about new issues, which then informed the next round of research and design activities. In this way, we deliberately iterated between analysis and design. Initially, the experiments were conducted in isolation from the daily practices of patients and clinicians, but later, when the prototype was more mature, we cautiously tried it out in the real life practices of patients and clinicians.

The overall project ran from 2008 to 2013 and we collected and produced empirical data throughout the period, using qualitative techniques such as interviews and observations, but also through collection of artefacts and documents used in patients' homes and in clinics. Interviews and observations took place in patients' homes as well as at the clinics. In the beginning, the purpose was to develop an overall understanding of who was involved in which types of activities and for which purposes. Later on, more detailed interviews and observations focused on specific treatment and care activities (including self-care) seen from the perspectives of the various actors. Interviews and observations were documented and selected parts were transcribed. This included noticing the ways in which patients and physicians organise and use documents and artefacts, allowing us to develop in-depth understandings of current practices. Data were also produced from workshops, prototyping activities and design interventions (See Bratteteig et al. and Brandt et al. in Simonsen and Robertson [2013](#)). The final use and system evaluation was

conducted as a user test with patients and clinicians performing several pre-determined tasks, while being observed by a researcher who had not taken part in the design activities. Also, both patients and clinicians were interviewed about their use experiences (Nielsen 2015).

We engaged in extended collaboration with 47 patients and 11 clinicians. To participate, patients needed to meet the following inclusion criteria; have an ICD implanted, be enrolled in remote follow-up, have a reasonable level of health literacy to articulate problems and challenges, have broadband internet access and a desktop computer, and finally live in the greater Copenhagen area. The clinicians represented 2 different hospitals in the capital region of Denmark, and were all engaged in ICD care on a daily basis.

4.4. Analysis

In our data analysis, we followed the interpretive approach (Walsham 1993; Klein and Myers 1999; Walsham 2006), iterating between understanding the whole and its parts and going over the raw material many times until we were able to form a coherent and solid interpretation of the subject matter. Firstly, we coded our material by labelling emerging analytical themes and then grouped and consolidated these themes into more general concepts.

Secondly, based on these concepts, we then chose four cases that we believe illustrate the concepts and their implications, and which in sum show how the divergent meanings of illness and disease play out in situations of designing and evaluating IT support for active patient participation in e-health.

5. Findings

We present our findings by analysing four empirical vignettes from our research. The idea is to illustrate the different challenges involved in aligning the concerns of patients and clinicians. There is a progression in presentation of the four vignettes, starting with a relatively simple example of a negative patient-clinician collaboration and ending with a more complicated, but also more positive example. For each vignette, we discuss how it illustrates a key challenge in the process of aligning concerns.

5.1. Case #1 – What is a meaningful concern?

In this vignette, we highlight the difference in how patients experience illness and how clinicians conceptualise disease and, furthermore, how this difference comes to designate what is perceived as important and meaningful in the communication by each party.

Louis is 51 years old and has had his ICD for only a year after suffering a sudden heart attack. In his case, the experiences of becoming a heart patient and an ICD patient melt into each other. Louis is recovering from the heart attack and suffers

from various symptoms related to the heart disease itself, the device and the medication. In addition, Louis feels anxious and depressed. He ascribes this partly to the trauma of experiencing his own mortality, partly to the lack of continuity of care and partly to the incoherent and often incomplete information he receives from various health professionals (see Figure 2).

Louis is, therefore, enthusiastic about the prospect of new ways and means of communicating with clinicians and engages very actively in the use of myRecord. He makes several notes on symptoms with the logbook feature (ranging from feeling tired, loss of breath and swollen legs to anxiety, and impotence) and is eager to utilise the preparation module prior to his upcoming medical follow-up. He also explores the network feature to connect and share experiences with other patients. He praises the potential of myRecord and explicitly links his positive assessment to his position as a new patient with a strong need to feel secure and 'in control' and to be able to raise urgent questions and seek continual professional guidance.

Having completed the preparation via myRecord, where he has written an extensive prose text about his symptoms and concerns, Louis has high expectations for the upcoming consultation at the clinic. However, afterwards he is greatly disappointed, because the clinician did not respond to all of his specific concerns or attend to his situation at large:

'I was prepared for the consultation. And that thing regarding vitamin D, he didn't mention it. He didn't say anything to me. And regarding the legs, it was me who insisted, insisted, insisted [...] So, I was disappointed with the consultation, really.'

The cardiologist on the other hand felt that he was able to react to the patient's primary concern (which he perceived to be the experience of dizziness and loss of

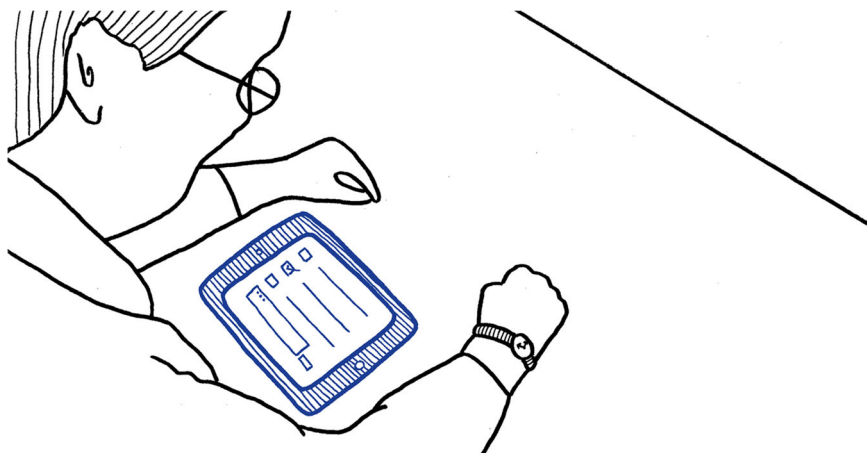


Figure 2. Louis using myRecord to prepare for an upcoming consultation by writing in his Logbook

breath, and which he linked to a possible adjustment of medication). He left the rest unspoken, since it was not something for him to act on:

‘Because he [Louis] was allowed to write about it and he had made that list, I could just say to him; ‘I can see you’ve written something about this and that. This is the main thing for you,’ and we could then go straight to that topic without having to start all over. So, I think it’s a good way to manage the contact.’

The cardiologist further indicated that he thought the very act of writing down his concerns would make Louis feel better, and that Louis would also ‘feel heard’ by knowing that the cardiologist had read his preparatory notes. This case illustrates how a clinician and patient can have conflicting perspectives on 1) which concerns are important and relevant for the consultation, and 2) what constitutes as a proper (re)action. The cardiologist perceives his role as managing the consultation so that most important concerns – seen from his perspective – are addressed. Further, myRecord allows him to be a passive listener, which he believes will indirectly satisfy the patient. The patient, however, feels quite the opposite, and finds much of the follow-up meaningless, stating that in order to be meaningful to him, his efforts must result in a ‘real’ (re)action at ‘the other end.’

5.2. Case #2 – Is action possible at all?

In this vignette, we take this issue of a proper reaction a bit further by illustrating the second challenge that plays an important part in the process of aligning concerns. Namely, it is not enough for a concern to be meaningful. The concern needs to be actionable as well; that is, the relevant party should be able to take appropriate action to deal with the concern (see Figure 3).

Ann, an experienced ICD patient, is eager to test myRecord in the hope that it could improve her life with the ICD. Her case illustrates that even when an issue is in principle perceived as relevant and topical by both patient and clinician, the lack of ability to act on this issue means that her concern cannot be aligned with clinicians’ concerns, and communicating about it through myRecord proves futile.

Ann is preparing for a remote follow-up of her ICD device by filling out the preparation form. When asked about her general well-being, she states that she ‘is doing fine’. When moving on to describe events and symptoms she writes: ‘Neck-vein nuisance caused by electrodes and in some periods swelling, scar tissue?’ This entry refers to her persistent experience of pain in her right shoulder and neck caused by the ICD device pressing on a vein – a concern she has raised several times before. After the remote follow-up the lab technician who has read Ann’s preparation form and consulted the device data responds that if the symptoms get any worse, she should call them.

When interviewed about the correspondence, Ann explains that she appreciates the lab technician’s response but also states that it would not make sense for her to take it up



Figure 3. Ann using myRecord in a remote follow-up. She describes her symptoms in the Preparation form

again this way. The clinicians are unable to take action, since it has already been established that re-positioning the device is too risky. Communication cannot solve this problem. It could be argued that the concern raised by Ann, according to herself for sake of the experiment, is actionable in some ‘lesser’ sense; the lab technician’s response is an act – perhaps an act of care – and he feels he has acted in the sense of reacting with an instructive message: ‘call if it gets worse.’ But although Ann appreciates this reaction as a caring gesture, from her perspective it was not a meaningful exchange since it did not really entail action. In this case, myRecord did not align concerns as the concern raised by the patient was not actionable. Importantly, while there may be ways and situations in which an e-health service can *make* action possible, some issues will remain outside the scope and problem-solving potential of e-health.

5.3. Case #3 – Who can act?

This third vignette illustrates another variant of actionability. It shows how a concern raised by a patient is – in principle – clinically actionable; however, the ability to act rests with another clinician than the receiving clinician.

In a distributed care setting, clinical responsibilities are both formally and practically distributed. This means that although patients may have concerns of clinical relevance (e.g. critical side-effects of medication), they may only be relevant for clinicians with a certain speciality. However, when patients write questions and describe their concerns in an e-health service like myRecord, they are often not aware of or sufficiently attentive to what kind of clinician they are writing to. Hence, the patients risk writing things that are of little relevance to the clinicians. The patient needs therefore to be able to assess what is relevant to whom, if the e-health service is to provide help. In other words, the patient must at some level understand the

‘infrastructure’ of the distributed care scheme. The e-health service could indicate or assist in this.

The participant Ben is preparing for the upcoming in-clinic device follow-up at his heart centre by filling out the step-by-step preparation form in myRecord. When he reaches the section where he can state his most important questions for the clinician, he writes that he is very concerned with his blood pressure, because he finds himself increasingly exhausted when performing his daily tasks at work. Eager to find a solution so that he can keep working, Ben asks to have his blood pressure monitored over the course of a day at work (see Figure 4).

During the consultation at the outpatient clinic, the lab technician and the cardiologist quickly browse through Ben’s preparation form on their computer screen while asking him about his general well-being, his medication and specific symptoms related to the ICD. Ben then asks about the possibility of having his blood pressure monitored and brings forth a referral letter for a local hospital, which he has received from his general practitioner. The cardiologist briefly answers that it is not something she can get into, and that he will have to take it up with the local hospital.

Afterwards Ben describes how he was ‘disappointed about the fact that they hadn’t read through it carefully. It just goes helter-skelter, you know. [...] Then it’s just ridiculous to write about it (his concerns)’. Given that Ben had put much effort into preparing for the visit by using myRecord, he expected the clinicians to have been prepared to address his concerns. This was, however, in his opinion not the case. Their lack of interest and action in relation to his concern about his blood pressure made him feel that his preparation had been meaningless. The cardiologist on the other hand, stated how she was able to ‘browse through what he had written’ while she was with the patient, and that the preparation form ‘worked well’. It did not bother her that she was presented with a concern of the patient that she was not able

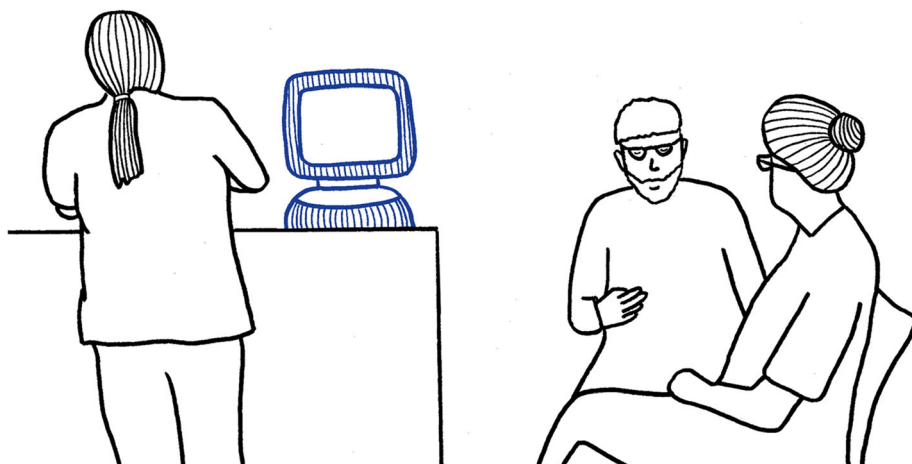


Figure 4. Ben at the consultation. The lab technician and the cardiologists only act on what they find relevant from the information that Ben has entered in myRecord

to act on for organisational reasons. Rather, she found it useful to be able to quickly browse through the patient's concerns and screen out those she did not have to pay attention to.

This vignette highlights that although the concern raised was both meaningful and clinically actionable, it was not *feasible*, because it was outside the cardiologist's scope of responsibility and therefore too difficult and cumbersome to deal with. Although the cardiologist was pleased with myRecord and not at all bothered by being confronted with a concern that she was unable to take action on, the patient, on the other hand, found the encounter demoralising and disappointing due to what he perceived as an unsatisfactory 'absence of action.'

The case is also indicative of how difficult it is for patients to gauge clinicians' interests and how discouraging the response may be. For Ben, this experience was such a disappointment that he ceased to use myRecord. This supports our claim that motivation for use rests on the existence of aligned concerns and of the e-health service's ability to support these. In this case it fails to do so because it is unable to facilitate a 'match' between the concern of the patient and the concerns of the clinician in question.

5.4. Case #4 – Alignment of concerns with myRecord

While the three previous vignettes illustrate how myRecord was unsuccessful in supporting meaningful patient participation in health care treatment, the following vignette shows how other features of myRecord allowed for enhanced collaboration. In remote monitoring, patients are excluded from engaging with clinicians and both parties rely primarily on the data recorded by the ICD device. With remote monitoring, patients only have a few ways to ask questions and raise concerns, for instance by calling the clinic in opening hours.

In design interventions with different versions of myRecord, we experimented with ways to fulfil the needs of both patients and clinicians by (a) enabling patients to supplement transmissions of ICD data with notes on their own experiences and (b) by enabling lab technicians and cardiologists to include patient generated data in their interpretation of ICD data and to respond in more effective ways.

Consider the case of Irene who is 57 years old. Irene was born with a congenital heart defect and has therefore been undergoing chronic care since an early age. The implantation of an ICD in 2005 has added to her anxiety, particularly because of inappropriate electric shocks (erroneous and severe ICD treatment) and her continuous experiences of arrhythmia. Irene feels that her health is 'fragile', as she says, and she has lately begun seeing a psychologist, which has improved her well-being. During a design intervention of a remote follow-up with myRecord, Irene transmits her ICD data from home as usual, but this time she also uses myRecord to answer the question 'how are you feeling' by writing:

‘Up and down – I’ve experienced being dizzy several times and have had the same feelings as when I got atrial fibrillation in 2008 [...] When the feeling arises, it makes me feel quite insecure, partly because I get dizzy, partly because I’m afraid of what it is.’

Irene approves her medication list, selects the appropriate medical categories, writes about her worries, and enters the specific dates and times where she has experienced dizziness and symptoms like atrial fibrillation: ‘Registered episodes have been: 01.10, 11.10, 31.10, 05.11 (at 8.40 and approx. 12.15 to 13.00).’

The following morning at the heart centre, the lab technician reviews the transmitted ICD data and concludes that there have been no therapies and that no events are recorded. However, when she consults myRecord and reviews Irene’s writings and medication list, the lab technician decides to re-visit the recorded ICD data and the device settings. The lab technician concludes that the device is set up appropriately and decides to continue with her standard procedure and send the standard letter to Irene, affirming that ‘the system is fine.’ However, provided with the possibility of easily dictating an individual reply to patients in myRecord, the lab technician decides to take action and comfort Irene by explaining what the device data show:

‘Hi Irene, it’s the lab technician at the heart centre [...] I can understand that you feel uncomfortable and I have therefore checked the episodes you are mentioning. But the device has not recorded atrial fibrillation. So, when nothing is registered in the zones that we’ve set it up to monitor, I can assure you that the atrial fibrillation is well controlled and that you do not enter any critical zones [...] so, it’s really great that it works well with your medication [...]’

This illustrates how myRecord supported Irene in raising concerns in a format that the lab technician could use in her work of checking that the ICD device was configured correctly. The symptoms and concerns described by Irene were of particular interest to the lab technician because the device settings need to be configured in correspondence with symptom experiences. Further, it enabled the lab technician to decide on proper action with improved confidence, improving her decision-making in remote monitoring (see Figure 5).

Moreover, the possibility provided by myRecord of easily making a voice-dictated and individualised reply, enabled the lab technician to accommodate the concern of the patient. In the language of e-health, myRecord supplemented the existing form of remote follow-ups and created favourable circumstances for active patient participation. To a certain extent, the features in myRecord allowed for the alignment of the patient’s ‘reality’ (feeling anxious about symptoms of irregular heartbeats) with the clinician’s ‘project’ of



Figure 5. The lab technician consulting myRecord together with ICD data and providing feedback to Irene

ensuring high quality telemonitoring (device settings are set properly, and the patient is notified in a comforting manner).

6. Conceptual guidelines

Based on these findings, we present a set of conceptual guidelines for designing patient-centred e-health services. The concepts are grounded in insights from medical phenomenology (Baron 1985; Toombs 1992; Carel 2011), in analytical reflections from the participatory design and in our empirical findings regarding the use of myRecord. These conceptual guidelines accentuate the importance of ensuring that e-health services align or reconcile the divergent needs and perspectives of patients and clinicians. Furthermore, they recognise the decisive gap in how patients experience illness and how clinicians conceptualise disease and suggest the importance of working towards designing e-health services that specifically seek to reconcile these, often divergent, concerns. Below, we present three properties that are essential for the identification and alignment of concerns in this context. The properties are meaningful, actionable, and feasible.

6.1. Meaningful

This initial property designates how a concern of one party (e.g. the patient) can only become a concern for the other (e.g. the clinician) if it is ‘meaningful’ to both, for instance by being acknowledged as clinically topical or relevant to the treatment and care process. Case 1 and 2 illustrate this by showing how concerns that are meaningful to Louis and Ben are not necessarily considered meaningful by the responding clinicians.

A meaningful concern is, however, not a static entity. It can evolve as patients, for instance, become more experienced in doing their clinical ‘homework’. This may result in more informed and more detailed answers that can aid their own task of coping with the everyday challenges of their illness. As patients become more proficient in using myRecord, they might also become better at providing clinicians with the information they need to improve their treatments. Accordingly, clinicians may begin to consider the patients’ concerns as relevant. This, in turn, can lead to an increased support of the patients’ needs. Still, concerns only align if they are found to be meaningful by both the patient and the clinician.

6.2. Actionable

In all four cases, we pointed to a second required property – namely, that a concern has to be ‘actionable.’ Meaningful concerns arise as topical, clinically relevant and worth communicating about only when it is possible to take action on the concern. In other words, the concern needs to be actionable to be taken into consideration.

In the fourth case, myRecord facilitated the patient’s articulation of a concern that proved relevant for both parties as it provided important information about symptoms not reflected in the ICD data. That is, the patient and the clinician succeeded, with support of myRecord, to make the concern actionable. By giving the lab technician the opportunity to quickly and easily respond verbally to the patient with a comforting message, a certain kind of action was made possible (an action of care, we might call it). In other words, the lab technician’s (re)action made it meaningful for the patient to continue to raise her concerns, i.e. use the technology, whereas in the case of Ben and Louis this did not happen.

6.3. Feasible

A concern may be meaningful and actionable (in principle), but difficult or even impossible to handle by the clinician receiving it, e.g. due to the division of labour between medical specialties and/or professional and organisational boundaries. In the third vignette, we showed how a lack of knowledge about the ‘infrastructure’ and distribution of care let the patient to raise concerns that were simply beyond the scope of the clinician’s responsibility. While myRecord succeeded in assisting the clinician in ‘handling’ this concern by allowing her to quickly disregard it, the patient was not assisted in directing the right concern to the right clinician. As a result, the patient found his efforts and the e-health service meaningless. Hence, concerns put forth by means of an e-health service need to be ‘feasible.’

To be feasible, a concern must not only be actionable in principle, it must also be easy and convenient to take appropriate action within the organisational and social context. For example, to mitigate the above mentioned problem of ‘misdirected’ requests from patients, one could maybe

design the service so that it supports clinicians in re-delegating action to the appropriate actor or so that it supports patients in addressing their questions to the right actor. In some cases, action may be delegated to patients themselves, for instance as a self-monitoring task or medication administration. In such cases, a concern may then be feasible if the patient is capable of and willing to act as recommended. Thus, feasibility should be understood as appropriate delegation of tasks between actors in both home and clinic. These findings are summarised in Table 1.

7. Implications for designing patient-centred e-health

Using the three concepts – meaningful, actionable and feasible – we recommend that designers of e-health services consider a number of important questions at specific times in the process (see Figure 6). The three-step e-health design process, described below, provides inspiration for how to proceed and which questions to ask at what time.

Designing for alignment of concerns is a challenging undertaking that ideally requires prolonged interaction with both patients and clinicians. It requires more than a traditional requirements specification process, because it calls for an extended commitment to understanding the different types of users’ perspectives (Fitzpatrick and Ellingsen 2013) through collaborative design activities. Working to align concerns is particularly

Table 1. Conceptual guidelines for aligning concerns in e-health

	Definition	Example
Meaningful	A concern is meaningful when it – at the same time – fits the biomedical model of medicine and the lived experience of patients	A patient approaches the cardiologist with a wide range of concerns that in number, character and style contrasts with what the cardiologist finds meaningful. The (lack of) response in turn makes the encounter meaningless to the patient.
Actionable	A concern is actionable when clinicians and/or patients – in principle – are able to take appropriate action	A patient is concerned that she has irregular heartbeat (arrhythmia). The lab technician at the heart centre takes appropriate action by making a short reply where she comforts the patient and assures her that she does not have arrhythmia.
Feasible	A concern is feasible when it is not only actionable in principle, but also in practice easy and convenient for clinicians or patients to take appropriate action.	A patient is concerned with his blood pressure and asks the clinicians at the heart centre to have it monitored. The request is, however, outside the scope of their responsibilities – and thus not feasible.

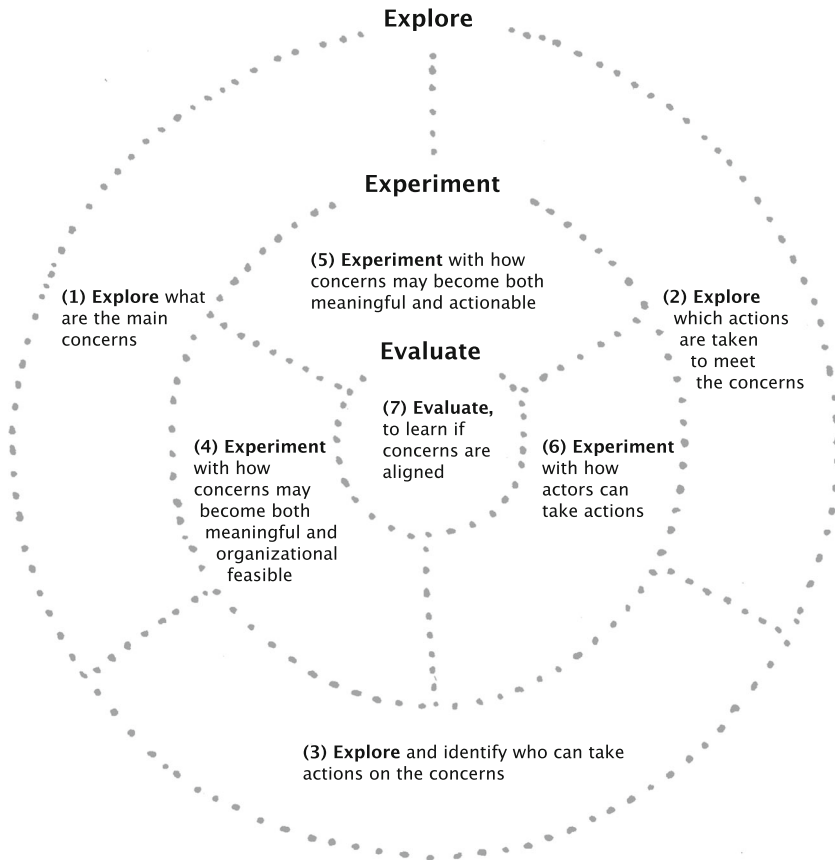


Figure 6. The model illustrates the three modes of activities that are useful when designing patient-centred e-health services that seek to align concerns. It is based on the relation between the three concepts: meaningful, actionable, and feasible. We recommend starting in the outer circle and moving inwards in an iterative process

demanding in terms of ensuring the articulation and negotiation of both patients' and clinicians' concerns. Seeking compromises and establishing a consensus can be highly contentious, and not something that is easily achieved in one go. As we have shown above, patients and clinicians have inherently divergent goals and focus on different aspects of illness and disease. Aligning concerns is an active, collaborative process that requires continuous translation and adjustment between what is regarded as meaningful and feasible by both patients and clinicians. We, therefore, recommend applying a participatory design approach where prospective patients, informal caregivers and clinicians are actively involved throughout the process.

Participatory design methods (Bødker et al. 2009; Simonsen and Robertson 2013) can be tailored to identify and reconcile divergent needs and concerns by co-designing. Within health informatics, co-design is increasingly suggested as a way forward (Clemensen et al. 2007; Pilemalm and Timpka 2008; Hardisty et al. 2011). This involves

research and design techniques such as ethnographic field studies, design workshops, scenarios, mock-ups and prototyping. We suggest organising the participatory design process in iterative cycles involving three different modes of inquiry to support alignment of patients' and clinicians' concerns. The three modes are exploration, experimentation, and evaluation. Figure 6 illustrates how designers can design patient-centred e-health that is meaningful, actionable, and feasible in a three step, iterative process.

7.1. Explore patients' and clinicians' concerns

It is worthwhile to begin by exploring questions such as: 'what are patients' and clinicians' main concerns?'; 'which actions are – or are not – taken to address these concerns?'; and 'what are the responsibilities of patients and the involved clinical actors?'. This provides the design team with an overview of the existing practices in the patients' homes and in the hospitals, and it allows the design team to develop an in-depth understanding of the degree to which current concerns are meaningful, actionable and feasible to the different actors. These exploratory studies should also involve prospective users in prioritising and negotiating concerns. In this first step, 'alignment of concerns' serves as an analytical lens for exploration.

7.2. Experiment with aligning concerns

As soon as the designers understand patients' and clinicians' concerns, they should start experimenting with new forms of IT support and new ways of organising treatment and care to better align these concerns. Here 'alignment of concerns' serves as a generative concept. The design team should involve both patients and clinicians in experimenting with how concerns may become at once meaningful, actionable, and feasible as well as identifying which concerns may never be aligned. Often, some form of negotiation is needed to ensure that one party understands that in order to get what they want, they have to do things that make the e-health service relevant for other parties. Sometimes, this may simply not be possible, meaning that there is a limit to what can be achieved by any given e-health service. For example, when designing myRecord, clinicians were interested in getting information from patients when data in a remote follow-up indicated a worsening condition. Here, the clinicians realised that in return they had to provide feedback to the patient to accommodate the patients' concerns. In any case, supporting alignment of concerns entails shaping not only to the e-health system, but also the organisational context and the work practices involved.

7.3. Evaluate the degree to which concerns are aligned

As the project evolves, new tasks, roles, and ways of collaboration are created. At first, we recommend that experiments be conducted in isolation from the daily practices of patients, relatives, and clinicians. The reason is to avoid doing harm or violating concerns that the design team has not yet understood properly. However, as

prototypes become mature enough, we suggest cautiously evaluating these in settings as close to real life situations as possible ‘to see the degree to which concerns are aligned’. Ultimately, this means trying out prototypes in patients’ homes and in clinicians’ work environments in order to evaluate the degree to which they are, in fact, meaningful, actionable, and feasible in practice.

7.4. An example of the application of the conceptual guidelines

To illustrate how the conceptual guidelines can be applied to the design of specific features that support alignment of concerns, we present an example from a follow-up project, the SCAUT project (see Andersen et al. 2017). The example is a retrospective account of how we developed a new Symptom Tracking feature to replace the Logbook feature, which failed to ‘bridge the gap’ between patients and clinicians (see sections 5.1 and 5.3). The original Logbook feature was essentially a free-text diary, which was shared with clinicians. The Symptom Tracking feature, in contrast, applies a more focused and structured approach. It allows patients to track their symptoms by selecting from predefined clinical categories (or by defining their own categories) and score the level of severity of each symptom on a scale from 0 to 10 by using a ‘slider’ (see Figure 7). The Symptom Tracking feature helps clinicians get an overview of the patient’s symptoms and their development over time. We support this by presenting a summary of the data as a bar chart next to the data transmitted

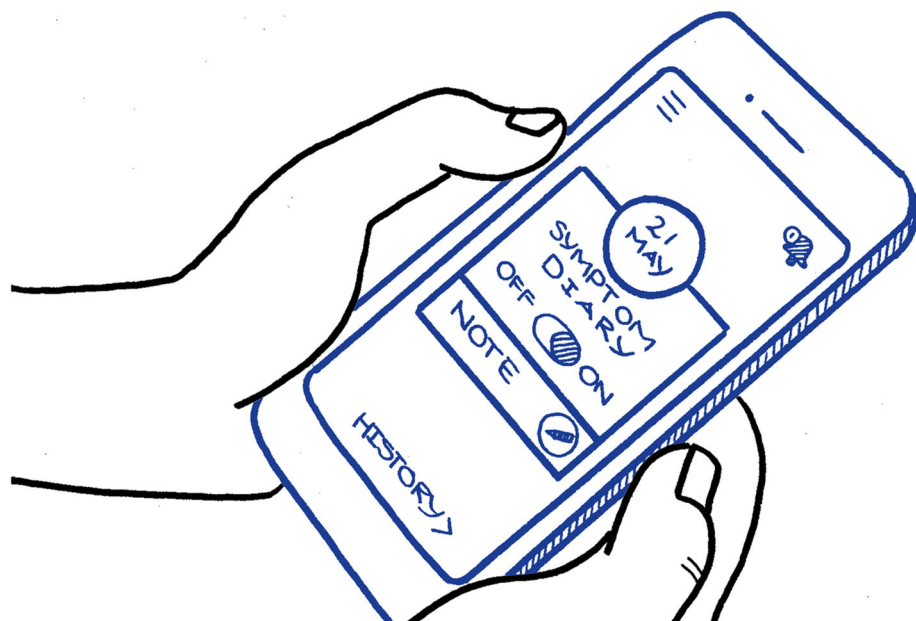


Figure 7. The Symptom Tracking feature in the SCAUT mobile app for patients where patients can turn it ON/OFF

from the patient's ICD over periods of one, three, and six months (see Figure 8). In the following, we explain how we arrived at this solution through an iterative process of data collection, prototyping, testing and refining the feature.

Exploring patients' and clinicians' concerns. In the first phase, our aim was to uncover and explore the concerns of patients and clinicians in regards to tracking of symptoms (see Figure 6; the first layer 'Explore'). Not surprisingly, we found that symptom experiences play a large role in many ICD patients' sense of health and well-being. ICD patients experience a variety of symptoms and they often worry about what they mean. In interviews, they described how they find it comforting and meaningful to share and discuss symptom experiences with clinicians, either by calling the clinic during 'telephone hours' or by asking lab technicians when they visit the clinic for follow-ups. We also discovered that some patients take notes of their symptoms on paper or in their smartphone calendar to aid their memory. For some patients, it is a learning process in which they gradually understand the reason for and the clinical relevance of their symptoms. For other patients, it is more about being comforted by the clinician and reassured that their symptoms and distress are taken seriously. Getting feedback on symptom experiences are therefore one of the main concerns of many ICD patients.

The clinicians' concerns are to some extent overlapping. When interpreting the data transmitted from a patient's ICD, either as part of a routine follow up or as a result of an 'event,' lab technicians and cardiologists need input from the patient about related symptom experiences. Clinicians are also aware of the importance of giving feedback and comforting patients when they are nervous or worried. In observations of phone calls with patients, we found that clinicians and lab technicians often focused on collaboratively making sense of symptoms in relation to the ICD data or on comforting the patient and ensuring him or her that 'everything looks



Figure 8. The cardiologist using SCAUT Clinic to get an overview of the symptoms tracked by a patient with severe chest pain

fine.’ In other words, learning about patients’ symptom experiences when needed and being able to give relevant feedback are important concerns for the clinicians.

Experimenting with different possible solutions. In the second phase, we engaged in *experimenting* with different solutions together with patients and clinicians. The purpose was to come up with a design that could align their concerns and make them meaningful, actionable and feasible for both parties (see Figure 6; the second layer ‘Experiment’). We visited patients in their home and used paper sketches and mock-ups to discuss a proposal for a ‘Symptom Diary’ feature (a forerunner to the Symptom Tracking feature that we ended up with) and we held workshops with clinicians to discuss how to visualise the recorded symptoms in an appropriate way and how to provide feedback to patients in an efficient and effective way.

The conclusion was that both patients and clinicians could relate to the idea of a ‘Symptom Diary’ or ‘Symptom Tracking.’ However, it was still not clear how to design a solution that would satisfy both parties. We considered different solutions. For instance, using a ‘rich’ medium like audio recordings to capture and transmit symptom experiences or, instead, using predefined or user-defined symptom categories and rating scales to record symptoms in a more structured way.

After some deliberation, we decided to try out the use of audio recordings. So the first version of the Symptom Tracking feature enabled patients to do just one thing: Namely, record a 30 s audio clip about their symptom experiences. At that time, recording and sharing symptom experiences by using audio seemed to align patients’ and clinicians’ concerns in a good way: They both found symptom experiences meaningful; patients could easily capture symptom experiences and share them with clinicians, and clinicians could access the recordings whenever they wanted to know about a specific patient’s symptoms.

So, we took the design sketches and ‘user stories’ to the software developers who in a couple of weeks developed a working prototype of the Symptom Tracking feature, ready to be tested by patients and clinicians.

Evaluating and redesigning the solution. In the third phase, we set out to *evaluate* the Symptom Tracking feature in real use and with real data (see Figure 6; the center layer ‘Evaluate’). We visited patients in their homes, observed clinicians at the Heart Centre, and learned about their opinion of the solution. It quickly turned out that many patients did not use it, because the purpose of tracking symptoms was unclear to them and because they found it too time consuming: “If I should note down and share symptoms every time I felt something, then I could do nothing but that... because is it a symptom or is it just my imagination? (design intervention in patient’s home, May 2016) (ibid.). However, other patients used it extensively. For example, in one case, a patient recorded multiple audio clips about his experiences of severe chest pain – and this proved to be a challenge for the clinicians. Listening to a few recordings could be very useful but reviewing and responding to many recordings from the same patient was extremely time consuming. So we had to realise that the use of audio clips was not feasible. It was

considered cumbersome and inconvenient by many patients and it did not scale well seen from the point of view of the clinicians.

Based on these learnings, we re-explored, re-experimented and re-evaluated several versions of the Symptom Tracking feature to see how we could make it more meaningful, actionable and feasible to record and share symptom experiences. For example, we dropped the audio recordings and instead asked patients to select a symptom category and rate the level of severity by simply using a 'slider' with a scale from 0 to 10. We also introduced the use of bar chart visualisations to help clinicians get an overview of the symptoms in an easy, fast and convenient way (see Figure 8). Furthermore, to ensure that patients would understand the purpose of the feature, we included a guidance video in the mobile app where a patient and a lab technician explained why and how to use the Symptom Tracking feature.

However, despite these improvements, the clinicians still did not find the tracking and sharing of patients' symptom experiences feasible. They were afraid that the feature would lead (some) patients to expect that they would get feedback on all kinds of symptom experiences, and this would simply not be possible in a busy clinical setting.

To mitigate this challenge, and thus improve the alignment of patients' and clinicians' concerns, we have introduced a number of changes in the current version of the feature. Patients must now actively toggle Symptom Tracking 'ON' in the mobile app (see Figure 7). When doing so, they are notified that clinicians will *only* review the symptoms if the ICD has reported an 'event' or if the patient explicitly has indicated a worsening of symptoms by clicking 'YES' to the question. In collaboration with the clinicians, we also developed a more efficient way to provide feedback to patients, namely a 'Standard Reply' feature, which allows clinicians to simply select from a list of standard replies.

The current version of the Symptom Tracking feature works much better than the free-text Logbook, but it is still not perfect and not as good as the other collaborative features we have developed in the project. However, it provides a good illustration of how we have applied the conceptual guidelines to design a solution that facilitates the alignment of concerns between patients and clinicians – even in a case where there is a 'minimum of overlap' between the two parties' concerns. During the whole process, we have been guided by the concept of 'alignment of concerns.' In the exploration and evaluation phases, 'meaningful,' 'actionable,' and 'feasible' have served as sensitising and analytical concepts, raising questions and opening up new lines of inquiry. In the experimentation phase, the concepts have played a more generative role, both by inviting further clarification and elaboration of the design problem and by stimulating creative thinking.

8. Implications for CSCW research

While the conceptual guidelines and methodical approach presented in this paper are aimed at designing patient-centric digital services to support treatment of patients with a specific chronic condition, there are strong indications that it will become increasingly important to focus on the alignment of concerns between patients and

clinicians in a wider context of healthcare. In this section we therefore discuss the extended implications of our conceptual guidelines for research.

As mentioned in the introduction, e-health research and development has for a long time focused on supporting different clinicians and other health professionals in their work. Although clinicians cannot be considered a homogenous group with entirely shared concerns, they do, after all, to a larger degree share perspectives – and concerns – with each other than with their patients. However, much of e-health research and development appears to view e-health design as a matter of supporting collaboration between people with relatively similar concerns, even when designing patient-centred e-health services, while often failing to recognise the complexity of the challenges at hand. This approach is perhaps further fueled by the strong associations between e-health and idealistic discourses about shared care, patient empowerment and so-called ‘participatory medicine’ (Weitzel et al. 2009; Gallant et al. 2011). We suggest that moving beyond this one-sided approach requires a more ‘holistic’ theoretical approach – one that is less prescriptive and more analytical in its understanding of patient-clinician relations. Sparked by empirical insights and our experience with the difficulties of designing e-health systems that align the often divergent concerns of patient and clinicians, we have found medical phenomenology inspiring (Baron 1985; Toombs 1992; Carel 2011) for its attention to fundamental differences between patients and clinicians. Furthermore, we have translated this phenomenological perspective and made it relevant for designing patient-centred e-health by devising conceptual guidelines.

Several societal trends underline the importance of focusing on the alignment of concerns among patients and clinicians. First of all, multimorbidity has become the most common chronic condition in itself (Tinetti et al. 2012). This means that more patients are at the same time treated for multiple, chronic diseases and often by different, specialised health professionals (Bussche et al. 2011; Agborsangaya et al. 2012; Moth et al. 2012; Barnett et al. 2012). In practice, the challenge is therefore to ensure the meaningfulness, actionability, and feasibility of a patient’s concerns, not just with one type of clinician, but with a large, heterogeneous ensemble of organisationally distributed health professionals, and vice versa. This emphasises the importance, yet also the complexity, of supporting patients and clinicians in aligning their concerns. To fully anticipate the consequences of multimorbidity, some questions regarding alignment of concerns remain to be explored: In cases of multimorbidity, the patient will often interact with several communities of highly specialised health professionals, potentially with different (sets of) concerns. What is meaningful, actionable, and feasible may therefore differ from one context to the next, making alignment of concerns even more challenging. Also, as traditional health management programs typically focus on single conditions and do not stipulate interactions between combinations of chronic disease, it is common that care interventions intersect and produce adverse and some times unforeseen effects (Boyd et al. 2005). Therefore, it is of crucial importance to investigate the need and

potential for aligning concerns among different groups of clinicians as well as to explore how this can be accounted for in our conceptual guidelines.

Furthermore, the appropriateness of traditional biomedical treatment goals is increasingly being discussed. For instance, in the emerging discourse on goal-oriented care (Mold et al. 1991), the traditional biomedical model of problem-oriented care is criticised for a lack of concern for the patient's desired outcomes and for a lack of ability to support coordination between different treatments. In the problem-oriented approach, therapy is mandated using condition-specific indicators and guidelines designed to achieve a certain target (Singer et al. 2002). In contrast, a goal-oriented approach to care is mandated by functional goals defined by the patient, for instance regarding symptoms, physical functional status, and mobility (Mold et al. 1991; Reuben and Tinetti 2012). A goal-oriented approach will require more attention to patients' perspectives, and it will become even more important to render their concerns meaningful, actionable and feasible for the clinicians.

Taking these observations a step further, it is important to highlight that many other actors, and thereby concerns, play a role in healthcare practices and innovation and thus should be acknowledged as relevant participants. This is increasingly recognised in participatory design of health IT (Kanstrup et al. 2017). These actors include hospital managers, administrators, policy-makers, relatives, and commercial companies (in our case, ICT manufacturers, see Andersen et al. 2017). This further complicates the task of aligning concerns. While it is beyond the scope of this article to further flesh out and exemplify how this complexity of concerns can be accounted for in design of digital services, we recommend the methodological approach outlined above as a guideline for further investigations. Moreover, and as a final note, the growing interest in frameworks like value-based healthcare and patient-reported outcomes may prove valuable for the alignment of concerns among multiple actors, with patient experiences being the privileged starting point.

9. Conclusion

In this article, we have sought to provide reflexive analytical concepts for informing the design of patient-centred e-health services. We started out by recognising the shift from hospital information systems to e-health and the new challenges that arise when extending the healthcare network to include patients as active, participating users. We then presented important insights from medical phenomenology regarding the general differences between patients' and physicians' perspectives, while also recognising the variation of concerns within both groups, suggesting that it is crucial to take these insights into account when designing and evaluating e-health services. With this overall conceptualisation as our analytical point of departure, we unfolded four cases from the design and user tests of a working prototype, myRecord, demonstrating the implications of patients' and clinicians' different concerns in the specific contexts of ICD-care and the need for appropriate alignment of these. That is, when designing e-health services to support collaboration between patients and clinicians, it is important to identify the

concerns that are *meaningful* to both patients and clinicians and, moreover, which concerns are or can be made *actionable* and *feasible*.

In our analysis, we identified the consequences of introducing e-health into existing care networks and how this complicates care. However, we have also demonstrated how e-health provides opportunities for new forms of care where active patient participation improves clinical decision-making and the quality of healthcare. Introducing a personal health record for ICD patients and the involved professionals turned out to reproduce, and even underpin, existing challenges of empowering patients to engage more actively in chronic care. The version of myRecord, featured in the first three cases, made the decisive gap between patients and clinicians more tension-filled and dissatisfactory for at least one party, often the patient. In these cases, the e-health service did not succeed in tapping into or supporting the alignment of concerns between patients and clinicians. More specifically, the prototypes of myRecord failed due to a persistent mismatch between the patients' and clinicians' respective perceptions of what constitutes a meaningful concern, and subsequently an appropriate action. In the final case, however, we showed how the service succeeded in aligning concerns by facilitating a translation of the patients' concerns into clinically meaningful issues and making them clinically actionable and organisationally feasible.

The somewhat contradictory outcomes of the design and use of myRecord illustrated by the different cases only underpin the necessity of developing theoretically grounded and empirically informed concepts for e-health, as we believe the concepts put forth in this article – alignment of concerns – to be. Echoing research that suggests participatory design and co-design as a way ahead (Clemensen et al. 2007; Pilemalm and Timpka 2008; Hardisty et al. 2011), we recommend operationalising the concepts by engaging in participatory design activities that employ a strategy of iterating between exploring, experimenting, and evaluating to enable the necessary collaborative process of identifying and negotiating concerns. The fact that the heterogeneity of patients' and clinicians' perspectives in practice may be even more complex than indicated by classic medical phenomenology only underlines the importance of approaching the alignment of concerns as a participatory and iterative process. This is also an encouragement for CSCW researchers to *experiment* with collaboration, guided by well-founded analytical resources and an awareness of the intricate dynamics between such different actors as patients and clinicians, yet without losing sight of the ambition to *design*.

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